No Wrong Door Planning Process
Focus Group Summary
February 18, 2015

Introduction

- In preparation for Colorado's No Wrong Door (NWD) planning process, eight focus groups were conducted – three with front line staff and five with consumers of long term services and supports (LTSS) and their caregivers
- The purpose of the focus groups was to learn more about how both groups experience the process of connecting consumers to LTSS and to identify "points of pain" (issues and challenges) in the current system

Methodology

- Seven focus groups were held via conference call; one was held in person
- Participants in front line staff focus groups = 27
  - Vast majority serve in case management and/or intake roles
  - Seven work with older adults, eleven with people with disabilities, six with both, three serve in other roles
- Participants in consumer/caregiver focus groups = 42

Consumer/Caregiver Focus Group Breakdown

Participant Description	Aging System	Disability System	Both
Consumer*	1	14	3
Family member/caregiver	3	14	0
Advocate/other	0	5	2

* Three consumers also experienced being a care giver for an aging parent

Findings

- Focus group findings are presented by segment and question
- Responses are listed in approximate frequency order (first bulleted response came up most often, second response was second most often, etc.)

Consumer/Caregiver Focus Groups

What kind of non-medical services do you use regularly?

- In home services (homemaker, C.N.A./ personal care)
- Day programs (aging and disability)
- Mention of specific waiver
- Specific therapeutic services (mental health, occupational therapy, etc.)
- Caregiver support (CDASS, respite, etc.)

What do you remember about how you first got connected to those services?

- Learning about/getting connected to services was largely/exclusively self-directed
  - Required significant self-advocacy/"hounding"
  - Limited/no proactive provision of information or direction
- Transition = going through the process all over again (from nursing facility; moving between counties, aging out of system, etc.)
- Experienced obstacles in eligibility process (functional and/or financial)
- Referred by healthcare system, school, peer, or community resource center
- Reported positive experience (esp. concierge, connected by healthcare provider)
- Given false, incomplete, inconsistent, or inaccurate information (experienced as ignorance/incompetence → outright deception)
- Overwhelmed by complexity of process and amount of paperwork

What worked really well about that process?

- A specific agency or staff person
- Having an advocate/learning to self-advocate
- Once we got in, the services really met our needs (esp. children w/ disabilities)
- Increases in consumer choice/policy changes in the past 2-3 years

What didn't work well? Or at all?

- Services were lacking (quality, transportation, gaps for certain conditions like TBI)
- Varying case management quality (turnover, caseload, limited knowledge of options)
- Siloes between agencies (no coordination, failure to share options, abuse, retaliation)
- Eligibility = poverty, job loss/ restrictions on working
- Lack of information, follow up, and transparency
- Specific regulatory/ policy issues, very easy to lose benefits

If we were starting from scratch, how would you have it work? If you could make just one thing easier about getting connected, what would it be?

- Break down siloes between agencies, ensure consistency
- Create tools to help consumers navigate the process (roadmap, directory, navigators)
- Simplify policies/ regulations
- Streamline paperwork/ red tape
- Regular, consistent communication, consistent messages across system

Frontline Staff Focus Groups

What are the biggest issues facing agencies like yours?

- Gaps and limitations of existing system and regulations
- Increasing/changing consumer needs and decreasing/insufficient resources
- Waitlists (for intake, for services)
- Transition-related issues (citing many different kinds of transitions)
- Consumer-related challenges (crisis situations, etc.)
- Workforce issues

How do those issues impact your day-to-day work?

- High levels of emotional stress and frustration
- Get by on the "little wins"
- Unable to use our expertise
- Stuck in crisis management mode

How do they impact your clients?

- Increased mental and emotional stress for consumers and their families
- Delayed access to services
- Bureaucratic fatigue
- Many forced into poverty, some into homelessness

What does it look like when everything works like it's supposed to? What are the critical factors that help successfully connect clients to services?

- Connection to an effective advocate/learning self-advocacy skills
- Certain client attributes "stack the deck": English-speakers, existing family or community connections, not in transition
- The staff member's strong relationship with a specific person or agency

What are the ongoing obstacles to successfully connecting consumers to services?
- Structural and regulatory issues (esp. waivers, siloes between agencies)
- Too few community resources (esp. transportation)
- Staff capacity (high caseloads, time spent on phone and in crisis management)
- Client fears and misperceptions (e.g., asking for help leads to nursing home)

If you could change just one thing, what would make the biggest difference?
- Make regulations and policies more flexible
- Improve effectiveness of working across agencies
- Simplify information sharing and red tape
- Tools/messages to reach and educate clients about process and services (esp. "first timers" such as older adults accessing services for the first time)

What's the one thing people designing No Wrong Door need to know about consumers?
- It is hard for many (most?) consumers to keep track of all the details and steps
- Transitions are especially hard – and more are coming
- The process of connecting to services often has a negative emotional impact on consumers
- Invisible conditions (TBI, autism, mental health, etc.) exist, but still need services

About front line staff?
- We hate when the system doesn't work for consumers, it can be devastating
- Really high caseloads and more complex client situations
- We are dealing with high in-house turnover
- We are at the mercy of the financial eligibility process

Points of Pain
Consumers/Caregivers
- Lack of information/being in limbo regarding status, next steps, options, etc.
- Delays in getting connected to services/ loss of services for trivial reasons
- Restrictions on ability to work (policy- and/or reality-based), impoverishment
- Amount of paperwork and red tape
- Transitions as points of pain – starting over to get connected
- Feeling of being on their own to navigate a complex system

Frontline Staff

- Lack of information/being in limbo regarding status (esp. eligibility and changes in a client's status)
- Restrictions and gaps inherent in the system
- Powerlessness – being unable to keep consumers from falling through the cracks
- Having to say no/enforce rules of a system they see as broken
- Emotional toll of working with clients in crisis/emotional distress
- Workload (caseload + coping with high turnover)

Implications

NWD System

Challenges

- Gap between current system and one that is person-centered is significant
- Split responsibility for determining eligibility is not streamlined; time lags and other issues are reportedly exacerbated when a county adopts a team approach
- Referrals are limited (don't know, don't want to, it's not in my interest to refer)
- Siloes between agencies and waiver categories contribute to complexity
- Caseload and turnover significantly limits bandwidth of agency staff
- Complex process is often too much for consumers to navigate on their own

Opportunities

- Significant duplication in paperwork (opportunity to streamline)
- Some referral bright spots exist within the healthcare system
- Strong self-advocacy tradition and curricula within the disability community

NWD Planning Process

- Rules, regulations, policies, etc. are a major barrier to person-centered approach
  - Balance between person-centeredness and policy imperatives must be defined
  - Indicates a need for strong consumer/ caregiver presence and input
- Impacted by larger system issues outside the scope of the NWD system
  - Planners need to take these realities into consideration and seek workarounds for "immovable objects"
- Staff who see problems and obstacles have limited/ no ability to make change
  - Content expertise needed to design an effective quality improvement process
- Changes to the system will necessitate policy change
  - Policy implications must be thoroughly tracked throughout planning process